Written Testimony of
Shelley A. Hearne, DrPH
Executive Director, Trust for America's Health
Washington, DC

Testimony Before the
Health, Education, Labor and Pensions
Subcommittee on Public Health
United States Senate
Hearing on
Health Tracking: Improving Surveillance of Chronic Conditions and Potential Links to Environmental Exposures
March 6, 2002

Mr. Chairman, Senator Frist, members of the Committee:

Good morning. Thank you for the opportunity to speak here today on the importance of investing in our public health system, and particularly a nationwide health tracking network.

My name is Shelley Hearne. I am an environmental health scientist, with a doctorate in public health and nearly twenty years of experience in government, non-profit organizations, and academia. I currently serve as the Executive Director of the Trust for America's Health (TFAH), a non-profit organization whose mission is to protect the health and safety of all communities, especially those most at risk of environmental and other public health threats.

TFAH leads a coalition of organizations, including Mt. Sinai Center for Children's Health and the Environment, Physicians for Social Responsibility, and U.S. Public Interest Research Group that support nationwide health tracking as an essential step toward strengthening our public health system. Along with our coalition members, more than 60 health and environmental groups support and endorse the call for health tracking. The list of supporting organizations has been submitted for the record and includes such distinguished groups as the American Heart Association, the American Academy of Pediatrics, Aetna US Health Care, and the Association of State and Territorial Health Officers (ASTHO).

Health-tracking Could Prevent Chronic Disease – The #1 Killer of Americans Today

The proposal for a Nationwide Health Tracking Network came from the Pew Environmental Health Commission, of which I was the executive director, where we spent two years studying our nation's ability to identify and respond to chronic disease clusters. Let me be frank about our findings: America's public health system has been woefully neglected, putting all of us at risk. It lacks the resources it needs to meet everyday challenges and unexpected events. We know our public health system falls terribly short when it comes to protecting Americans from chronic diseases like cancer, asthma, and diabetes.

Chronic diseases are responsible for 70 percent of deaths in the United States and affect over 100 million men, women and children, more than one-third of our population. These diseases cost our country more than $325 billion a year in health care and lost productivity and account for 60% of personal health care costs. By 2020, chronic diseases are expected to afflict 134 million Americans and cost our citizens and our government $1 trillion a year.

While we know that a large proportion of chronic disease is preventable by lifestyle changes, such as quitting smoking, better diet and nutrition, and increasing physical activity, there is much that we still do not know about their causes. Regrettably, we lack the vital information that would help us prevent these deadly diseases because we have no system in place to monitor and track chronic disease and conditions. Coordinated disease tracking occurs only for infectious diseases like polio, yellow fever, and typhoid – diseases that a national tracking system helped us to eradicate in this country.

Many chronic diseases are on the rise, and many are appearing in clusters, suggesting a potential link to environmental factors. For example:

- In Fallon, Nevada, a community of about 8,000 people, 15 children have been diagnosed with leukemia in the last five years. Residents and health officials suspect contaminated water may be the cause, but without a tracking system in place, the community is powerless to prevent future illness.
- At least 25 people have been identified with multiple sclerosis (MS) in Wellington, Ohio - a town of 4,200. Residents worry about the health effects from a local iron foundry and adjacent landfill.
- A cluster of cases of Amyotrophic Lateral Sclerosis (ALS) or Lou Gehrig's Disease has been discovered among former employees of Kelly Air Force Base in San Antonio, Texas. Studies have identified 127 former workers who have been diagnosed with or have died from ALS. Health officials are investigating the base to determine whether environmental exposures to various toxic chemicals are linked to the disease.

Terrorist Attacks Reinforce Need for Health-Tracking

Clearly, there is a large gap in our public health knowledge. And the September 11 attacks have made this gap more obvious and dangerous than ever. The destruction of the World Trade Center is something that will remain engraved in our memories forever. Unfortunately, the environmental contaminants released from the wreckage may also have an everlasting impact on the health of those who were at the site, including the heroic firefighters, police officers, and emergency health workers who were our first responders. Although this Congress has allocated one-time funds to track the health of first responders at Ground Zero, the New York City firefighter unions are seeking federal funding for "lifelong [health] monitoring" for firefighters who worked at Ground Zero. The firefighter union leaders are calling for federal funding of the proposal because they suspect there will be long-term health effects from environmental exposures.

An initial analysis has already shown that 1,600 firefighters involved in rescue efforts at the World Trade Center have respiratory problems, according to the New York Fire Department. CDC will be releasing a survey this spring that will detail exposures suffered by many of those firefighters. The fact that this health survey has been done is good news because there is recognition of the need for health monitoring. But the truth is there should have been a baseline of health information in place long before the September 11 attacks. Had we been routinely tracking where and when people were getting sick and whether there was a relationship to factors in the environment, public health officials would not have had to resort to tracking pharmaceutical sales such as Kaopectate in New York City to gauge possible illnesses from exposures. Incidentally, New York's unconventional tracking is considered one of the better public health surveillance systems in this country. How much more would we know if we actually tracked people's health and their exposures instead of tracking how fast over-the-counter medicine is sold and monitoring the air in one location that may or may not represent actual human exposures?

The targeted health tracking of the New York City first responders is an important and necessary step, but we must do more. This is health information that would benefit everyone. Looking at Ground Zero we find there is no health tracking in place for the many people who live and work in the area. And if we look nationwide, we recognize that every community has the right to know what they have been exposed to and what the long-term health effects might be.

Unfortunately, without a coordinated and comprehensive system in place, much of the detective work is left for the community to discover. There are hundreds of communities around the country that have concerns about unexplained clusters of disease and potential environmental exposures. Many of you have probably heard from your constituents about the importance of chronic disease tracking as part of a coordinated public health infrastructure within their communities. In fact, each year there are thousands of requests from the public to investigate disease clusters. A nationwide health tracking system offers a cost-effective means to gather valuable information about chronic diseases and potential environmental links. Estimated to cost about $275 million annually, less than one dollar for every American, this network could help us identify what causes chronic diseases and, importantly, develop ways to prevent them. It is

clear that, compared to the more than $325 billion chronic diseases cost our nation each year, an investment in this prevention-focused network is a better use of our tax dollars.

While Congress is considering how to help the public health system be better prepared in the face of unprecedented health risks—whether from the increasing concerns of disease clusters or the unforeseen threats from chemical and biological terrorism—we must make sure investments are made in the right way. What we do to prepare for terrorist threats also should help us prevent the chronic diseases that are already killing millions of Americans every year.

Health-Tracking – Part of a Modern Public Health System

To meet this dual-need, we should modernize our crumbling public health infrastructure. First and foremost, we need strong, qualified leadership at the helm of our public health agencies. Let me take a moment to say I am truly dismayed that to date, the top federal public health leaders are not in place at the Centers for Disease Control and Prevention (CDC), the National Institutes of Health, the Food and Drug Administration, the Health Resources and Service Administration, and in the Office of the Surgeon General. Ensuring public health is more important than ever. These positions must be filled and they should be filled with people who have both medical and public health experience. Then we ought to invest in the tools and troops needed to wage, and win, this battle to protect America's health. We need more and better-trained public health officials, a state-of-the-art early warning system and communications network to help with greater coordination among various agencies protecting the public, better-equipped laboratories and hospitals, and tracking of chronic diseases and monitoring of environmental exposures. These investments will give us the nationwide infrastructure needed to protect the public's health. Today, I would like to talk more about this last component, health tracking.

The model envisioned by the Pew Environmental Health Commission called for modernizing our public health system to deal with today's broad health threats. One part was an early warning system that could pick up a terrorist or accidental chemical event in hospitals and poison centers. Another was for tracking the very diseases that account for 70% of American's death and disabilities. The other was rapid response investigative capacity for clusters or emergency incidents. I have included a more detailed description of the network as envisioned by the Pew Environmental Health Commission at the end of my remarks.

In brief, a Nationwide Health Tracking Network would provide our communities, scientists, physicians, hospitals, and public health officials with important missing data on when and where chronic diseases are occurring, as well as environmental factors that may be linked to them. This will help us identify what causes these diseases and begin to develop ways to prevent them.

This issue is of great concern to the American public. In fact, 63% think that public health spending is more important than cutting taxes, and nearly three out of four registered voters (73%) think that spending on public health is more important than spending on a national missile defense system. In a 2000 poll by Princeton Survey Research Associates, nine out of ten registered voters (89%) indicated support for the creation of this national health tracking system.

Recent reports demonstrate the value of health tracking. Most recently, TFAH released a report card on birth defects registries in the fifty states, Puerto Rico, and the District of Columbia. Unfortunately, most states are doing a very poor job of tracking birth defects, the number one cause of infant death in this country. As much as 80% of birth defects are of unknown causes. Improved birth defects tracking as part of a larger health tracking network would help us identify what causes birth defects and work to prevent them.

Similarly, the Trust for America's Health issued a report last spring which found that more than half (27) of US states have no ongoing system to track and monitor asthma. Asthma affects more than 17 million Americans, including nearly 5 million children, and has been on the rise for the last 20 years. But we do not know why. As with birth defects and other chronic diseases and conditions, a Nationwide Health

Tracking Network would help us identify asthma clusters so we can uncover the causes and work to prevent the disease.

This Nationwide Health Tracking Network would build on disparate tracking systems already in place in some states to ensure coordinated, comprehensive data collection mechanisms in all 50 states and the District of Columbia. It would be cross-cutting, incorporating data from all the relevant branches of the CDC, and the Agency for Toxic Substances and Disease Registry, as well as other related agencies, like the Environmental Protection Agency (EPA).

Next Steps

So, where do things stand today? The good news is that the CDC already has the authority to create a Nationwide Health Tracking Network and has begun to do so. To date, Congress has appropriated $17.5 million for health tracking for pilot projects in several states. CDC will request applications from states for these pilot projects in April or May of this year. Critical components of the pilot projects have been developed in a series of workgroup meetings sponsored by CDC. As with any new project, there are strengths and concerns. One of the greatest strengths in the development of the nationwide health-tracking network is the inclusive process involving members of the health, environmental, public health and academic communities, as well as state public health officials to help ensure coordination and effectiveness.

There are, however, a few serious concerns that we feel must be addressed. CDC has created a new branch within the National Center for Environmental Health to oversee this program. This is problematic because the goal of a Nationwide Health Tracking Network is to take a broader look at data collection among different centers within CDC, giving the network the tools it needs to begin to pinpoint potential links between chronic diseases and environmental exposures. This network can only live up to its potential if there is full cooperation among the many different relevant programs both within and outside the CDC. The long-term goals of the Network will be undermined if this program is buried in one branch of one division of one center in this complex organization.

To ensure its effectiveness and accountability, Congress should also clearly define a home for this Network within the CDC. The Network should build on existing systems and have the status and resources necessary to cut across various agencies. There is no need to build an entirely new program within CDC, but we do need to begin to change the way of doing business at the agency. You can help by weighing in with your colleagues and the Bush Administration about the importance of establishing a coordinated and comprehensive Health Tracking Network that cuts across all the individual programs within the CDC.

Likewise, with the extraordinary investment of $1 Billion that the Congress and the Administration has just approved for bioterrorism preparedness, we need to seize this opportunity to do it right. To build a public health system that meets the needs of today and can be responsive to any unknown threats of tomorrow, we need the appropriately trained and mobilized troops, better communications systems, better prepared laboratories and comprehensive and coordinated tracking systems that would be a critical piece of the Nationwide Health Tracking Network. This strong public health defense system will need the leadership from you in Congress, from our Administration and from our public health officials around the country. In addition, we will need to pledge our continued support – real, sustained resources over many years.

These new funds are intended to strengthen state and local preparedness for bioterrorism. Specifically, the money is being made available for states to improve their infectious disease reporting systems, increase hospital and laboratory capacity, and improve communications systems. We hope that state and local public health agencies will finally be able to address the deficits that have been caused by decades of underfunding but this requires a much broader approach than just creating a system that is responsive to bioterrorism. Investing in the fundamentals of public health would prepare us for both bioterrorism or chemical threats and serious ongoing chronic illnesses.

As the nation's leading public health agency, CDC will play a vital role in the disbursement of funds for bioterrorism preparedness. CDC has prepared detailed guidance for the systems that need to be developed, and states are currently preparing their applications for HHS review. If CDC is going to oversee the development of the nation's reporting systems to improve national preparedness, CDC's own internal coordination must be improved, encouraged, and adequately supported. Although there is $1 billion in new funding to CDC for local, state and federal public health preparedness activities, it is not clear that it can be used to develop a coordinated and comprehensive public health infrastructure that will allow our communities to be prepared for bioterrorism and chronic diseases by including tracking and monitoring of chronic diseases and conditions and their potential link to environmental exposures.

Congress has a key role to play here. You can help by providing the CDC with the mandate and the resources it needs to turn this good idea of health tracking into a promising reality for communities across this nation and help coordinate it with the unprecedented resources now available for bioterrorism preparedness. The legislation proposed by Senators Clinton, Reid, and others is an important step toward ensuring the establishment of a comprehensive, coordinated Health Tracking Network as a critical component of improved public health infrastructure in America.

Finally, Congress must assure the resources are there to expand the pilot projects into a program that covers the entire nation. Specifically, Congress should allocate $275 million per year – less than one dollar for each US citizen – to establish a Nationwide Health Tracking Network. This investment represents just one tenth of one percent of the overall spending on health care in this country, and substantially less than the annual cost to our country from chronic diseases and conditions.

Without this important investment, we will continue to stand by and watch as asthma, cancer, birth defects, Alzheimer's, multiple sclerosis and other diseases continue to rise, and while our children, parents, friends, and colleagues continue to suffer, without any hope of explaining why or acting to prevent their suffering.

A nationwide health-tracking network is a highly cost-effective means to improve the public health system, our ability to prevent disease, and our capacity to detect and respond to health epidemics. You can support this initiative identified in the President's budget as a priority for the Centers for Disease Control and Prevention by assuring funding within the FY03 LHHS Appropriations process and by becoming an original co-sponsor of the bill that is soon to be introduced in both the House and the Senate. It will benefit the government and society through savings in healthcare costs and lost productivity and, ultimately, could help save lives by preventing disease. We cannot afford to do anything less.

There are five basic components of the Nationwide Health Tracking Network:

- *Establishing essential data collection systems*: The Network would build on existing health and environmental data collection systems and establish data collection systems where they do not exist to ensure uniform coverage in all 50 states. The Network would track chronic diseases like asthma and cancer, developmental diseases like autism and cerebral palsy, and neurological diseases like Alzheimer's and Parkinson's. It would also track environmental exposures to things like pesticides, lead, and air and water contaminants. With federal resources such as funding, training, and lab access, state and local public health agencies will collect, report and analyze the data.

- *Developing an Early Warning System*: A nationwide health tracking network would also serve as an Early Warning System to alert communities immediately of health crises, such as lead, pesticide and mercury poisonings, or biological or chemical acts of terrorism, like the recent anthrax attacks *(or such as the intentional release of chemicals in a community's water supply).*

- *Creating Rapid Response Teams*: To improve our response to already identified disease clusters and other health crises, the Network would coordinate federal, state, and local health officials into rapid response teams to quickly investigate these health problems. The Network would also provide these teams with trained personnel and needed equipment, all of which would help in responding to chemical or biological attacks.

- *Addressing unique local health problems*: Beyond the priority diseases established in the network, twenty regional and state pilot programs would allow for investigation of local health crises and disease clusters. These programs would alert public and health officials to new developing disease clusters, and would serve as models for tracking systems to be included in the nationwide network.

- *Creating community and academic partnerships:* Finally, the Network would establish relationships with communities and academic centers. Community relationships will help ensure that the data collected is accessible and useful on a local level. Relationships with research groups will allow us to train the workforce, analyze data, and develop links between the tracking results and preventive measures.